1994

A study of older adult knowledge of Parkinson's disease

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A STUDY OF OLDER ADULT KNOWLEDGE OF PARKINSON'S DISEASE

A Thesis

Presented to

The Faculty of the Department of Health Science

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

by

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December, 1994

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ABSTRACT

A STUDY OF OLDER ADULT KNOWLEDGE OF PARKINSON'S DISEASE

by Ann P. Oliver

This study obtained data on older adults' knowledge about Parkinson's disease (PD). Knowledge assessed included information regarding the etiology, epidemiology, symptoms, diagnosis, prognosis, treatment, and management of PD. Participants included 216 older adults, ranging in age from 50-98 years, who responded to a questionnaire consisting of 10 demographic questions and 26 knowledge questions on the Parkinson's Disease Quiz (PDQ). Nine subjects knew nothing about PD. Only 46% of the respondents answered 18 or more of the 26 questions correctly. More educated subjects, women subjects, and subjects diagnosed with PD or who had personal connections with PD scored higher on the PDQ than the other subjects. No differences in PD knowledge were found by age or racial/ethnic group. The study revealed that older adults lack depth of knowledge about PD.

ACKNOWLEDGMENTS

I want to extend sincere appreciation to the following individuals for their support and assistance:

To my advisor, Dr. Debra David, for her constructive recommendations and helpful guidance;

To Dr. Lela Llorens, for her encouragement and useful suggestions;

To Dr. Robin Fross, for her medical expertise and knowledge of Parkinson's disease;

To Merry Lee Hooks, OTR, and others at The Parkinson's Institute for their suggestions and important information;

To Pyone Cho for his valuable assistance with the statistical analysis of this study;

To Geralyn Mathews, for her help in printing this thesis on the laser printer;

To all the older adults who volunteered to participate in this study; and last but not least,

To my husband, Bud, for his patience, understanding, and help during the many months required for this study.

TABLE OF CONTENTS

LIST OF FIGURES

Page

LIST OF TABLES

Continued...

List of Tables continued Page

CHAPTER 1

INTRODUCTION

Purpose

The purpose of this study was to investigate the knowledge of Parkinson's disease (PD) held by older adults. The study explored the knowledge base that older adults might have regarding the etiology, epidemiology, symptoms, diagnosis, and prognosis of this common neurodegenerative disease. Further, this study examined older adults' awareness of treatment and management of the disease to improve the quality of life for people diagnosed with PD.

Statement of the Problem

Parkinson's disease is a progressive and disabling neurodegenerative disorder that can be physically, emotionally, and economically devastating to patients and families (Ellenberg, 1991). There are many older adults who have or may become affected by this disease. It can be postulated that many of these older adults, their families, and friends may have inadequate knowledge or misinformation about PD. They may be unaware of treatment and management

of this disorder that can improve their quality of life. If older adults do indeed lack adequate knowledge of PD, they may be confused about its cause and may lack an understanding of the unique needs, vulnerabilities, and experiences of people living with PD.

The need for increased awareness and understanding of PD came to the researcher's attention while working as a physical therapist with patients who have PD and their families. It was observed that people can be encouraged and motivated to access optimal health care for PD if accurate information and knowledge about the disease is made available to them. Also noted was that early identification and treatment of this disease can be important, since recent developments of drug therapies may slow the progression of the disease (Tanner, 1992).

The names of Harry Truman, Mao Tse Tung, Francisco Franco, and Adolf Hitler are instantly identified by most people, "but few realize that aside from shaping modern history, these renowned figures suffered from Parkinson's disease" (Lieberman, Gopinathan, Neophytides, & Goldstein, 1994, p. 1). No one is immune to PD; it can affect anyone from teenage years through senescence (National Parkinson Foundation, Inc., 1993; Lieberman et al., 1994). However, it is primarily a disease of people who are over 40 years of age and usually begins between the ages of 50 and 65.

It is difficult to date exact onset because initial symptoms are subtle and progression is gradual, but the average age of onset is approximately 61 years (Duvoisin, 1991). Parkinson's disease is one of the most common ailments and crippling disorders of older adults in the United States. It has become a common neurodegenerative disease in the aging population, surpassed in incidence only by Alzheimer's disease (California Parkinson's Foundation, 1990). Lieberman et al. (1994) stated the following regarding the knowledge of the disease:

> Most physicians and laypeople are not aware of PD's true impact and do not realize that more people suffer from it than multiple sclerosis, muscular dystrophy, and amyotrophic lateral sclerosis combined. Few diseases have remained so anonymous while affecting so many people. (p. 1)

Parkinson's disease is expected to become more prevalent due to projected increases in life expectancy and the population of older adults. Also prevalence of the disease increases with age, especially after age 70 (Ellenberg, 1991). Therefore, it is important to know about this disease.

Question

The research question this study addressed was: What do older adults know about the etiology, epidemiology, symptoms, diagnosis, prognosis, treatment and management of Parkinson's disease?

Hypotheses

The hypotheses generated for this study were as follows:

1. Older adults who have been diagnosed as having PD or have family members or friends with the disease have more knowledge of PD than those respondents who have no personal connection with the disease.
2. Older adults with more formal education have more accurate knowledge of PD than those with less education.
3. White older adults have more knowledge of PD than older adults from other racial/ethnic groups.
4. Older women know more about PD than older men.
5. Older adults have more knowledge about PD than younger adults.

Definitions

Words and phrases used in the literature review, data collection, analysis, and discussion are defined in the following.

Conceptual

Bradykinesia: Abnormal slowness of movement.

Culture: The attainments and learned behavior patterns of a period, race, or people regarded as expressing a traditional way of life subject to gradual but continuous modification by succeeding generations (Standard College Dictionary, 1979).

Diagnosis: Act of distinguishing conditions from other diseases or disorders.

Ethnicity: Of or belonging to a particular racial, cultural, or language-specific group. Also belonging to a group that is distinguished by common features of language, customs, etc. (Standard College Dictionary, 1979).

Epidemiology: Study of the relationships of the various factors determining the frequency and distribution of diseases in a human community.

Etiology: Cause(s) or origin of a condition.

Improved quality of life: Ability for people to find increased enjoyment and appreciation of people and things in daily living.

Incidence: Number of cases of a condition occurring during a specific time interval.

Knowledge: Acquaintance with facts and truths.

Management: Act or manner of coping or controlling symptoms of a disorder.

Parkinsonism: Conditions clinically characterized by tremor, rigidity, bradykinesia, stooped posture and shuffling gait. These conditions include PD and other neurodegenerative disorders.

Parkinson's disease: A chronic, slowly progressive systemic neurological form of parkinsonism characterized clinically by the combination of resting tremor, rigidity, bradykinesia, and impaired postural reflexes. It is clinically defined by symptom improvement with Levodopa (L-dopa) that is the single most effective antiparkinson drug, which a native brain chemical changes into dopine in the brain.

Prevalence: Total number of cases of a condition in existence in a given population at a fixed point in time.

Prognosis: Forecast as to the probable outcome of a condition.

Rigidity: Abnormal stiffness or inflexibility of the limbs or spine. There are 2 kinds of rigidity often seen in parkinsonism: 1. "Lead-pipe" or "plastic" which is diffuse muscular rigidity. 2. "Cogwheel" in which the muscle tone

resists and gives way in a series of little jerks when muscles are passively stretched.

Treatment: Care of a person for the purpose of easing symptoms of various conditions.

Tremor: A regular rhythmic to-and-fro involuntary movement of small amplitude affecting a limb, the head, or the entire body. Typically PD rest tremor is a slow, regular, and rhythmic tremor in a body part that is not engaged in an action.

Operational

Elder and older adult: Subjects 50 years of age and older who participated in the study. The majority of the subjects were Santa Clara County, California, residents from Eastside Neighborhood Center, John XXIII Neighborhood Center, Yu-Ai Kai, Little House, Pilgrim Haven, Parkinson's Disease Exercise Class, and the Visiting Nurse Association.

Ethnic/racial minority group: The umbrella term for Hispanic Americans, African Americans, Asian Americans, and others of color who participated in the investigation.

Knowledge: The understanding of PD and an awareness of the treatment and management of the disease as measured by the older adults' responses to the questions on the Parkinson's Disease Quiz (PDQ).

White racial group: The umbrella term meaning all non-Hispanic Whites who participated in the study.

Assumptions

Assumptions within this study were as follows:

1. The majority of participants would be able to speak, read, and understand the English language and would comprehend the statements of the study and would answer truthfully and to the best of their ability.
2. The subjects of the study would honestly give their correct age of 50 years or older.
3. The subjects in the study would be of various ethnic and racial backgrounds.
4. The subjects participating in the survey would be members of both genders.
5. The subjects would include older adults with clinically diagnosed PD and those without the disease.
6. The participants would find this study educational and beneficial. By participating in this survey they would learn important facts and information about PD.

Limitations

Limitations in this study were as follows:

1. Due to constraints of time and subject availability, a sample of convenience was used. Subjects may have had a special interest in PD. Therefore, they may have been more

knowledgeable about the disease than the general population.

2. Due to their unfamiliarity with PD, some respondents did not understand the survey questions, even though someone was present and available to assist them.

4. Due to tremor, lack of muscle coordination, poor endurance, eyesight, or hearing, some of the elder subjects had difficulty completing the questionnaire.

5. Due to their advanced physical impairments, some of the prospective respondents were unable to participate in the survey.

6. Due to the use of the sample of convenience, the study sampled a skewed older adult population and can not represent a controlled data base.

Significance of the Study

It is believed that there are older adults who have been diagnosed or may be affected by PD or who are at risk of developing the disease, who lack knowledge about the disease. Schoenberg, Anderson, and Haerer (1985) found in their research in Copiah County, Mississippi, that their subjects lacked awareness and understanding of PD, and 42% of the identified cases were undiagnosed before the study. "Prior to the study, the undiagnosed persons had coped with

their symptoms without medical assistance" (Anderson & Kalton, 1990, p. 312). It can be assumed that there may be undiagnosed cases of PD in Santa Clara County, California. There also may be patients who have been clinically diagnosed with PD who need more helpful information about the disease. Awareness and understanding of PD are important for older adults because it can motivate those who think they may have symptoms of the disease to seek help from health care professionals. If the disease is diagnosed in the early stages, neuroprotective medications may slow progression of the disease (Duvoisin, 1991; Langston & Koller, 1991). Knowledge will allow for possible diagnosis of PD so that beneficial treatment and careful management of the disease can be given. Knowledge can help them live more comfortably with their symptoms, thus improving their quality of life.

The findings of this study provide important information to health care professionals, especially those treating older adults and those treating patients who have PD. The findings should help health care professionals understand the need to present more useful information about PD to both the individuals who may be at risk of developing PD and patients who have been diagnosed with the disease.

CHAPTER 2

REVIEW OF THE LITERATURE

This chapter contains relevant information from the literature regarding the etiology, epidemiology, symptoms, diagnosis, and prognosis of Parkinson's disease (PD). It discusses treatment and management of PD and explains the difference between PD and other parkinsonism conditions.

A search of the literature was conducted to find studies that examined the knowledge of PD held by the general population, particularly older adults. Numerous research studies were found and reviewed that investigated the knowledge people have about other diseases, but no articles were found that examined people's knowledge and awareness of PD.

This chapter covers the following: parkinsonism and PD distinctions, prevalence and incidence of PD, causes of PD, treatment and management of PD, barriers to knowledge of PD, knowledge investigations of other diseases, conceptual framework for this study, and the summary.

Parkinsonism and Parkinson's Disease Distinctions

Parkinsonism

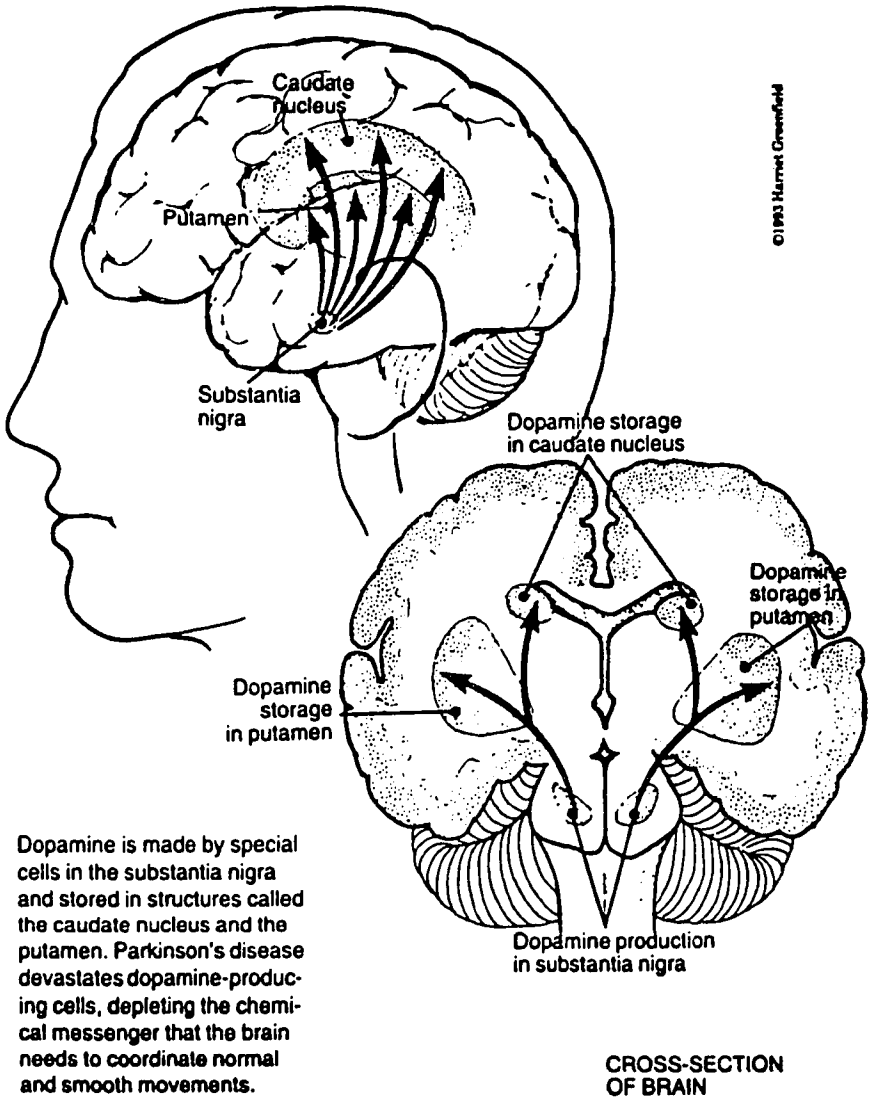
Parkinsonism is not a specific disease but it is a syndrome that refers to conditions commonly recognized by a characteristic set of symptoms (Duvoisin, 1991). The conditions of parkinsonism include PD and other neurodegenerative disorders. Tanner (1992b) defined the syndrome of parkinsonism as characterized by four symptoms that are the same as the cardinal signs for PD. These symptoms or signs are (a) slowness of movement, called bradykinesia; (b) increased muscle tone or rigidity, causing increased muscular resistance to an examiner's passive movement of the limb; (c) rhythmical shaking of a limb while at rest, occurring 3-5 times per second and often referred to as pill-rolling type; and (d) impaired balance known as postural reflex impairment. Other classic signs of parkinsonism that may also appear are stooped posture, gait with short shuffling steps, masked face, infrequent eye blinks, small handwriting, and speech that is hesitant, soft, and monotonous.

Parkinsonism is caused by a dysfunction of a particular system of melanin-pigmented cluster of nerve cells in the midbrain, known as the substantia nigra.

These nerve cells produce and store dopamine, which is a chemical critical in the function of the brain and nervous system. The nerve cells of the substantia nigra send thin fibers upward that connect with other nerve cells in the deep grey matter called the corpus striatum. Dopamine travels up these fibers and transmits signals to the nerve cells of the striatum (see Figure 1). If there is a substantial deficiency of dopamine, and hence neuronal activity, in the substantia nigra caused by injury or insult to these nerve cells, symptoms of parkinsonism begin to appear. Losing nerve-cells containing dopamine is a normal aging process, and it has been postulated that every individual living to be 110-120 years will probably contract parkinsonism (Kulmala, 1989).

Parkinson's disease, also known as classical, typical, or idiopathic PD or parkinsonism, is the most common form of parkinsonism. Many parkinsonism conditions resemble PD and all are the result, at least in part, of an injury or impairment of nerve cells in the substantia nigra, causing a deficiency of dopamine. Examples of these injuries are: toxic substance exposure and drug-induced parkinsonism; viral infections causing postencephalitic parkinsonism; arteriosclerotic parkinsonism from strokes; symptomatic parkinsonism from tumors, poisoning, or injury; and

Figure 1



Note. From "Parkinson's Disease" by Harriet Washington, 1993, Based on a two-part series published in the May and June 1993 Harvard Health Letter, p. 4. Reprinted by permission (See Appendix A).

parkinsonism-plus in which symptoms of PD occur along with other symptoms of the nervous system disease (Duvoisin, 1991).

Burns (1992) refers to parkinsonism-plus as atypical parkinsonism, multisystem atrophy, or pseudoparkinsonism. These multi-system degenerative disorders include conditions such as progressive supranucular palsy (PSP), striatonigral degeneration (SND), Shy-Drager syndrome (SDS), olivopontocerebellar atrophy (OPCA), and cortical basal ganglionic degeneration (CBGD) (Jankovic, 1992). These atypical parkinsonism disorders have a prognosis and response to treatment that is different from those of PD.

One of the best ways to determine if a condition is atypical parkinsonism or typical PD, is to observe the person's response to drug therapy. If a person does not show improvement when treated with levodopa, this indicates the possibility that the illness is not PD but is an atypical form of parkinsonism. Langston, Koller, and Giron (1992) note that the differences in clinical symptomatology of multisystem atrophy (MSA) and PD include (a) high prevalence of rigidity alone in MSAs while PD has both rigidity and resting tremor, (b) tendency of more rapid progression in MSAs, (c) more tendency for familial transmittance in some MSAs, and (d) typical poor response of MSAs to levodopa. Atypical parkinsonism syndromes

(MSAs) may collectively account for up to 20% of the cases of parkinsonism (Grimes, Gray, & Grimes, 1989).

Parkinson's Disease

Idiopathic, typical, or classical PD is a specific disease and as stated earlier is the most the prevalent type of parkinsonism. This disease was first recognized and described in 1817 as "the shaking palsy" by James Parkinson, who was a general practitioner in London, England. Paralysis agitans, meaning "shaking palsy" in Latin, continues to be the official name for this disease in the World Health Organization's International Statistical Classification of Diseases, although it is no longer used in the medical literature, superseded by Parkinson disease.

Parkinson's disease refers to a specific disorder limited principally to the substantia nigra and other pigmented nerve cells (Tanner, 1992b). It has been described as "a slowly progressive disease of the brain that gradually robs its victims of the ability to move" (California Parkinson's Foundation, 1990, p. 4). Parkinson's disease differs from other parkinsonian disorders because the affected nerve cells contain an abnormal structures called "Lewy bodies" that can be seen

under the microscope and are the pathological hallmark of PD (Duviosin, 1991). Levels of the nerve chemical dopamine in the striatum are usually reduced by 80% or more to produce the clinical symptoms in PD (Watts & Mandir, 1992). Langston, Koller and Giron (1992) estimate that a loss of 70% or more of substantia nigra neurons and a loss of 80% or greater striatal dopamine are necessary for PD symptoms to develop and be diagnosed.

At the present time there are no definite laboratory tests for diagnosing PD. The disease requires a clinical diagnosis that is established by a neurological examination based on signs and symptoms. Many patients do not know the exact date of onset and early clinical signs are usually subtle and difficult of identify (Calne & Snow, 1992). Imaging and laboratory techniques can identify or rule out other conditions but are not required for diagnosis (Paulson, 1993). In the future, analysis of blood, physiological tests and pathological tests may provide potential markers that can help with early detection of PD (Calne & Snow, 1993), but these are not currently available.

Langston, Koller, and Giron (1992) described PD as a distinct clinicopathological disorder with typical clinical features of rigidity, rest tremor, bradykinesia, and postural instability; neuropathological evidence of cell

loss in the substantia nigra; and presence of Lewy bodies on pathological examination of the brain. Hutton (1989) pointed out that PD is conventionally diagnosed when at least two of the classic clinical features are found, or when one major and at least two minor signs are found ("minor signs" include changes in speech, difficulty in swallowing, drooling, seborrheic dermatitis, stooped posture, lack of arm swing when walking, shuffling gait, balance loss, mask-like face, constipation, poor bladder control, and impotence). It has been noted that rest tremor is absent in about one-fifth of patients with PD (Hutton, 1989). Symptoms vary and few patients develop all the signs before diagnosis, but most patients in the late stages eventually develop all symptoms.

Lieberman, Gopinthan, Neophytides, and Goldstein (cited in Common Medical Problems: Parkinson's Disease, 1993) described a slightly different delineation of PD symptoms. They reported that the five primary symptoms are tremor, rigidity, bradykinesia, balance difficulty, and difficulty with walking. The secondary symptoms listed are depression, sleep disturbance, dementia, forced eyelid closure, speech problems, drooling, swallowing difficulty, weight loss, voiding difficulty, constipation, breathing difficulty, dizziness, stooped posture, feet swelling, and sexual problems.

A common type of neurological disorder, often mistaken for PD, is familial or essential tremor (ET). These more rapid tremors occur when a person is using his or her hands to maintain certain postures or actions. The major difference between ET and PD is that ET is an action tremor (occurs in limb in action) and PD is a resting tremor (occurs in limb at rest). ET usually affects the hands but can occur in the head or voice. There is no associated rigidity, bradykinesia or gait disorder. Often there is a family history of ET, and usually a long history of tremors (Grimes, Gray, & Grimes, 1989). Essential tremor is the most prevalent movement disorder in the U.S. Although there is no cure, it is treatable; it is not life threatening; it rarely has any other symptoms; and it won't lead to PD (Modern Maturity, 1993). It is important to distinguish ET from PD, because of the more favorable prognosis for ET.

Prevalence and Incidence of Parkinson's Disease

Parkinson's disease is a common neurological disorder usually beginning between the ages of 50 and 65 with the prevalence increasing in older individuals. Symptoms are uncommon before age 50 and extremely rare before the age of 30 (Tanner, 1992a). People under 40 years are affected

with an incidence of less than 1 per 10,000 (Grimes, Gray & Grimes, 1989).

Parkinson's disease affects approximately 1% of the total United States population over 55 years of age with this percentage predicted to increase significantly as the U.S. elder population increases. Up to 1,500,000 Americans have been diagnosed with the PD, although it is believed that there are many more undiagnosed or misdiagnosed cases (Parkinson NPF Report, 1994). It is estimated that 80% of adults over 65 have at least one chronic illness with prevalence increasing with age (Fried & Wallace, 1992), and PD may be one of these chronic diseases. The California Parkinson's Foundation (1990) claimed that 50,000 people in California could be projected to have PD. This number likely will be larger today with the continuing increase in the population of older adults in California.

Though precise comparisons are difficult to make due to differences in culture, medical care, and research designs, PD appears to occur with similar incidence and prevalence for all races in countries throughout the world where good epidemiological studies have been conducted (Duvoisin, 1991). Schoenberg, Anderson, and Haerer (1985) and Haerer, Anderson and Schoenberg (1987) found no evidence of racial difference in the prevalence of PD in blacks and whites in Copiah County, Mississippi. This

prevalence rate conflicted with the study by Kurtzke and Goldberg (1988) where age-adjusted death rates for PD in the U.S. were lower for blacks than for whites. That same study found PD in Asians in the U.S. to be the same as for whites. A prevalence study of PD in China (Li et al. 1985) seemed to indicate that PD was less common there than in other parts of the world, perhaps due to the fact that China is less industrialized or because of inadequate research methods and poor medical diagnoses. However, Dr. Zi-Cai Feng recently visited China and found the incidence of PD increasing with life expectancy in China (Parkinson NPF Report, 1993). Reasons for variances in incidence and prevalence findings are uncertain. There is insufficient information from existing studies to rule out possible racial/ethnic/national differences.

Parkinson's disease strikes men and women in equal proportions; most studies found no significant sex difference in the prevalence of PD (Tanner, 1992a). Schoenberg et al. (1985) found no substantial difference in the age-adjusted prevalence ratios by sex in their Copiah County study. Kurtzke and Murphy (1990) and Kurtzke and Goldberg (1988) reported a male proponderance of PD in the U.S. and Denmark but this may have been caused by geographical or environmental factors.

Parkinson's disease is expected to become more prevalent in the world due to the increase in life expectancy. This will be true in the United States where the population of older adults is increasing at a rapid rate. In this nation, those 65 and older accounted for over 3 million in 1900, 29 million in 1985, and in 2030 will reach 65 million (Greenberg, 1993). Among this number are the minority elders who are projected to grow at a rate more rapidly than the white elders, well into the next century (Barney, 1991).

This accelerated growth of the older adult population is occurring in Santa Clara County, California. According to a demographic report (Santa Clara County Strategic Planning Commission, 1990) there will be a dramatic increase in the number of older adults over 65 years of age in Santa Clara County in the future. The commission predicted that between the years 1985 and 2010, the population of these older adults of the county will increase by 79%. In the year 2010 13% of the total population will be over 65 years old, compared to 8% in 1985. The total number of older adults in the county in 2020 is expected to be 272,540; and most importantly, 26,000 of them will be over 85 years of age. Then one out of every five persons will be over 65 years of age (City of San Jose Aging Services Master Plan, 1994).

This growing older adult population in Santa Clara County will result in increased levels of more complex and diverse needs. Knowledge about PD is one of the important needs, because as the older adult population increases, the prevalence of PD also will increase. With this projected growth in the elder population and the fact that the prevalence rate for PD is about 1% of the total population over the age of 55, with percentages increasing as one grows older, in the future it may not be unusual to have a family member or close friend diagnosed with the disease. Parkinson's disease is not a fatal condition; therefore, there will be a continuing increase in the number of people with the disease (The National Parkinson Foundation, 1993).

Causes of Parkinson's Disease

There are many theories about the etiology of PD, but the cause of the disease still remains a mystery. Bissand (1895) as cited in The Case for the California Parkinson's Foundation (1990, p. 1) stated that: "Parkinson's disease remains so utterly inexplicable....that we are constantly drawn to it by the lure of the mysterious". Numerous studies and investigation seeking the etiology of PD have been conducted over the years since it was first described by James Parkinson in his 1817 Essay on the Shaking Palsy

(Duvoison, 1991). During the past few years ideas about neuronal cell death and important theories of etiology have been formulated and have led to promising research studies (Langston, Koller & Giron, 1992).

Kulmala (1989) and Duvoisin (1991) have suggested that there is no evidence that PD has a genetic cause. Martataila, Kaprio, Koskenvuo, and Rinne (1988) stated that PD is an acquired disease and not hereditary because of the prevalence of PD in twins compared with the prevalence in the general population. This does not, however, answer the question of genetic predisposition, because studies have shown a deficiency of liver enzymes in persons with PD, and enzymes are genetically controlled (Kulmala, 1989). Studies conducted show that the disease rarely affects both members of identical twins although follow-up studies ten years later may show delayed appearance of PD in previously unaffected twins. There are those who believe there is a familial tendency for the disease and that it may be inherited, but there is yet no solid proof to support this theory. Although there is little evidence that PD has a genetic cause, possible genetic factors continue to be under investigation. One research study presently being carried out at The Parkinson Institute in Sunnyvale, California is an investigation involving 21,000 twins to assess genetic and environmental influences involved in the

etiology of PD. The intravenous injection of the compound methylphenyl-tetrahydropyridine (MPTP) caused toxicant-induced PD in a number of young narcotic addicts. This suggested that in some cases exposure to an exogenous agent might cause PD (Tanner, 1992b). In Quebec, Canada, the incidence of PD was seven times greater in a farming region that had high usage of pesticides and herbicides than in a neighboring area with low pesticide/herbicide use. Well water in Saskatchewan is thought to be associated with the possible cause of PD at or before the age of forty. It was reported that 19 of the 21 people who contracted PD lived in the same area and all but one of them drank the well water (Kulmala, 1989).

Industrialization and increased exposure to industrial toxins is a phenomena being actively explored for its relationship to PD. Kurtzke and Goldberg (1988) found from mortality studies in the U.S. that more PD deaths occurred in the North than in the South, possibly due to greater industrialization in the North. A study in China (Tanner et al., 1989) found that enviromental exposure to certain industrial chemicals may be related to the development of PD. Studies have led many investigators to believe that PD may be caused by an interaction between toxicant exposure and heritable predisposition (Langston, Koller & Giron, 1992; Tanner, 1992b). There is agreement by many

researchers that the prevalence of PD increases with age, but the risk factor profile is unclear for this disease (Molgaarad, 1993). Therefore, studies continue to be conducted into the cause of PD.

Treatment and Management of PD

There is no curative treatment for PD but many palliative treatments are used. "An important element in the treatment of the disease is the interruption of symptoms, as well as advice and reassurance that an understanding and knowledgeable doctor can give" (Duvoisin, 1991, p. 58). Patients diagnosed with PD have available a variety of oral medications and other treatments, depending on their symptoms. Initially some require no drug therapy, while others will find certain drugs to be helpful for symptoms of tremor and rigidity. Paulson (1993) recommended the drug selegiline for all newly diagnosed cases, because it may have the potential to slow the disease process. Duvoisin (1991) believes that selegiline can slow the progression of the disease symptoms for at least 2 or more years and can delay the need for levodopa. Segegiline can also enhance the effects of levodopa. The search is continuing for other protective therapies that will slow or stop the progression of PD.

The drugs currently prescribed for the treatment of PD "act either by replenishing brain dopamine, mimicking the action of dopamine, or by modifying the function of the brain in such a way as to compensate in some degree for the deficiency of brain dopamine" (Duvoisin, 1991, p. 59). Until a better treatment or cure is discovered, once symptoms require palliation, drug treatment should continue for life. Olanow (1992) noted that "investigators are cautiously optimistic that the coming years will provide exciting therapies that may influence the natural progression of PD and lead to more effective treatment" (p. 2).

There are some surgical treatments for PD: stereotactic thalamotomy, stereotactic pallidotomy, adrenal-gland-to-brain transplantations, cell culture transplantations, and fetal tissue transplantation (the latter four are still experimental). Tremor and rigidity, primarily on one side of the body, often can be relieved by the well known procedure thalamotomy while the experimental pallidotomy is said to help relieve all symptoms of PD. Parkinson's disease occurs when approximately 80% of the dopamine-secreting cells of the brain are lost, and surgical teams are attempting to replace these lost cells by the implantation of dopamine-secreting cells into the brain. All the transplant surgeries are experimental,

controversial, and have yet to be proven totally successful. "Using present techniques, neural grafting will not cure Parkinson's disease and no data exist to suggest that implants will slow the progression of nigrostraital degeneration or provide any benefits compared with conventional pharmacological therapy" (Kordower, Felten & Gash, 1992, p. 212).

Treatment of PD can include the management of dementia because decline in thinking abilities is estimated to develop in about 12% to 25% of people with PD. This can affect many different mental functions such as short term memory, social judgement, language, reasoning and orientation, with the most common problem being loss of memory (Tanner, 1993). Tanner points out that there is no way to predict whether a person with PD will develop dementia. Dementia or changes in thinking can also be a result of medications used to treat PD symptoms. At present there is no useful treatment for dementia.

Depression is common and at least 40% of those diagnosed with PD experience depression at some stage in their illness (Grimes, Gray & Grimes, 1989). This condition is treatable, and so it is important to distinguish depression from symptoms of dementia.

Management of PD includes the rehabilitation team of physical, occupational, speech therapy, and psychsocial

therapies. This team develops specific goals related to the individual needs of the person with PD. Mobility and independence are the major objectives; to achieve these objectives, drug therapy must be augmented by suitable programs of the rehabilitation team. These non-pharmacological adjunctive therapies to medical management of PD are as important today as they when Szekely, Kosanovich, and Sheppard (1982) stated the following:

> Although there are no cures for Parkinson's disease, physical therapy, occupational therapy, speech therapy and psychosocial therapies may be utilized to curtail the morbid effects of immobility, social isolation, and psychological withdrawal, all of which may contribute to increasing disability and eventually incapacitation or institutionalization. (p. 72)

Support groups are also important in the management of PD. They are available in many locations and can be helpful to families and people with PD. Support group members exchange ideas and share information on means of coping with practical problems related to their disease. F. Seyfarth and J. Seyfarth (1986) state that PD "support groups will vary with the needs and talents of the individuals who shape and are shaped by them. And these individuals will discover that by helping others they have helped themselves" (p. 10).

Barriers to Knowledge of Parkinson's Disease

Barriers exist that may prevent older adults from receiving information that can increase their knowledge about PD. Barney (1991) and Yeatts, Crow, and Folts (1992) have suggested that barriers for older adults, especially elders of the racial/ethnic minorities, must be overcome in order for the older adults to receive adequate information and services. Many older adults are unaware of PD and have no information or misinformation available to them. Information about PD may be unclear, misunderstood, or not in a person's language, and this may severely limit his or her knowledge of PD. Parkinson's disease information should be readily available for older adults, and it should be easily accessible to them. Access barriers may cause difficulty in obtaining information about PD and may delay medical attention and prevent early diagnosis and treatment of this disease.

Fear or lack of desire to be informed about PD may limit knowledge and recognition of the disease. It is common for people to avoid revealing their lack of knowledge or understanding of a disease for fear of being considered ignorant (Dent & Goulston, 1982). Cultural practices, beliefs, and attitudes can limit or preclude motivation to seek information about PD or to use Western

medical care. According to Michielutte and Diseker (1982), lack of knowledge and attitudes are factors that may inhibit intent to access health care. Older adults may believe that the symptoms of PD are just a result of the aging process and an intent barrier (the negative perception of taking action) may prevent them from doing anything about the symptoms. Lack of knowledge of PD may result in the disease being undiagnosed or misdiagnosed as depression or, in the very old as "normal" aging (Tanner, 1992a).

Older adults need information that is relevant and appropriate for them. The information should be oriented in such a way as to reduce the barriers and increase the perception of the benefits of seeking professional help (Michielutte & Diseker, 1982).

Knowledge Investigations of Other Diseases

Numerous articles were found that reported investigations of the knowledge that individuals have about various diseases and conditions, but none were found regarding PD. It has been shown that people's knowledge about a disease or condition can influences their health related attitudes, beliefs and behavior. Further, there may be apathy or indifference among people toward learning

more about diseases. The American Cancer Society observed in 1980 that there may be a hesitancy toward obtaining information due to the fear people may have about a disease, believing that "what you don't know can't hurt you" (Berman & Wandersman, 1991, p. 1246).

Most studies conducted to measure the knowledge of cancer discovered that the demographic variables of race, education, age and gender have moderately high correlations with cancer knowledge (Berman & Wandersman, 1991). National surveys found that urban blacks have less knowledge of cancer than whites of similar social status, and educated females over 40 years of age have the most cancer knowledge (Berman & Wandersman, 1991). They also found that having a family member or close friend with cancer resulted in more knowledge of the disease.

Dent and Goulston (1982) found in their study using 10 cancer knowledge questions that females scored significantly higher than males and that participants 40 years or older scored better than those younger than 40. Their Australian survey found that subjects whose birthplace was an English-speaking country had significantly higher knowledge scores than those from other countries. They also found that the mean cancer knowledge scores varied little in respondents who left school at ages 14-18 years (inclusive), but those who had left school

before the age of 14 had distinctly lower knowledge scores. And those who went on for more education had significantly higher scores. Participants who had a relative, friend, or acquaintance with cancer also scored higher than those who had no personal connection with the disease (Dent & Goulston, 1982).

Individuals who have accurate knowledge of cancer "have lower fear of cancer, lower psychological distress, and tend to perceive greater efficacy in treatment methods" (Berman & Wandersman, 1991, p. 1245). Inaccurate knowledge and information may result in fear of a disease and influence health attitudes and behaviors. It is believed that this could also apply to the knowledge of PD, because accurate information is necessary to prevent fear of PD and to encourage appropriate attitudes and behaviors regarding treatment and management of the disease.

Michielutte and Diseker (1982) found that black adults had less knowledge of cancer than white adults when education, sex, and age were controlled. They suggested that possible reasons for this difference in knowledge were (a) the higher quality of education received by whites than by minority groups; (b) the tendency for whites to obtain information from written material while blacks tended to rely on television or radio that may be brief and incomplete; and (c) the lack of motivation by blacks to

acquire knowledge of cancer because of difficulty in accessing the medical system.

The first national survey on the knowledge of Alzheimer's disease measured perceptions and knowledge about the characteristics and symptoms of the disease (Cutler, 1987). The survey included demographic factors of age, sex, and educational differences, and the degree of knowing someone with Alzheimer's disease to assess if these factors were associated with accurate knowledge about the disease. Cutler (1897) found that 90% of the subjects said they had heard of the disease and about 50% said they personally knew someone with the disease. The major finding of his survey was that knowing someone with the disease, especially if the person was a family member or close friend, led to a greater level of knowledge.

Another study regarding older adults' beliefs and knowledge of Alzheimer's disease found respondents' knowledge of the disease was poor (J.A. Price, Shanahan, J.H. Price, & Desmond 1986). Their questionnaire measured knowledge in four areas: demographic characteristics of the disease; etiology; symptoms; and diagnosis/treatment and care. They discovered that more education was associated with greater knowledge of the disease. Respondents scored higher if they had a relative or friend with Alzheimer's disease. The researchers reported that the older adults'

source of information about Alzheimer's disease was limited and that there were many avenues available, such as programs, films, lectures, workshops and panel discussions, that would increase the public's knowledge regarding the disease. The study found that both the public and professionals lacked information about Alzheimer's disease.

Many studies have investigated the knowledge of AIDS and HIV in the U.S. population. One questionnaire survey determined whether knowledge varied by demographic characteristics of the population or by living in areas with a low, medium or high incidences of AIDS (McCraig, Hardy, & Winn, 1991). Their data suggested that knowledge is less dependent on where people live and more dependent on demographic factors. They found a lower HIV/AIDS knowledge score among black and Hispanic, persons with less than a high school education, and subjects 50 years of age and older. They pointed out that "new and continued efforts are needed to improve knowledge in older persons, minorities, and the less educated in all parts of the country" (McCraig, Hardy, & Winn, 1991, p.1591). White adolescents in the San Francisco School District were found to know more than blacks about the cause, transmission, and prevention of the HIV/AIDS; and black adolescents were more knowledgeable than their Latino peers (DiClemente, Boyer, & Morales, 1988). Another study found that HIV-related

knowledge among adults in the U.S. was less in subjects of lower socioeconomic status and racial/ethnic minority groups (LeBlanc, 1993). Lower levels of knowledge were found in older adults, men, those living outside the metropolitan areas, and those who cited television and newspapers as their primary source of information. The researcher concluded that awareness and understanding of HIV/AIDS is important, because "without a better knowledge of the basic characteristics of HIV, people will not only remain confused about the transmission of the virus, but also will continue to lack an understanding of the unique needs, vulnerabilities, and experiences of people living with HIV" (LeBlanc, 1993, p. 33).

Conceptual Framework

The framework for this study was based on the belief that knowledge about health and disease can be learned. Health education can be a major factor in the maintenance of health and prevention of disease. Many different explanations and responses exist regarding the symptoms, cause, process, treatment and prognosis of disease or illness. Kavanagh and Kennedy (1992) noted that a person's conceptual framework provides a way to interrupt the cues "that alert one to becoming or being ill and determine what

is done and why, as well as for maintaining health and preventing illness" (p. 20). The literature suggests that better knowledge about disease or illness can lead to more appropriate health behavior.

Summary

The review of recent literature on PD revealed that there are numerous articles describing the disease and many research studies being conducted attempting to unlock the mysteries of this disease. The literature described the attempts being made to discover new therapies that can influence the natural progression of the disease and lead to more effective treatments for PD. Investigators are beginning "to address the critical issues of etiology and pathogenesis, and to formulate a scientific rationale for therapies designed to protect against neuronal progression and to restore functions lost as a consequence of cell degeneration" (Olanow, 1992, p. 1).

Missing from the literature were studies that examined the knowledge held by the general population about PD. Investigations have been conducted that examined the knowledge people have about cancer, Alzheimer's disease, AIDS/HIV, polio, tuberculosis and other diseases and conditions (Berman & Wandersman, 1982; Culter, 1987; Dent &

Goulston, 1982; DiClemente, Boyer, & Morales, 1988; LeBlanc, 1993; McCraig, Hardy, & Winn, 1991; Michielutte & Diseker, 1982; Price et al., 1986). Most of these studies found that demographic and social variables such as age, gender, race, and education and knowing someone with the disease had a relationship to knowledge of the disease. It is likely that knowledge about PD would show similar patterns, but no information was discovered that reported the degree of public awareness and knowledge of this disease.

CHAPTER 3

METHODOLOGY

Purpose

The purpose of this study was to investigate the knowledge of Parkinson's disease (PD) held by older adults. The knowledge explored included facts about the etiology, epidemiology, symptoms, diagnosis, and prognosis that older adults should understand about this common neuro-degenerative disease. Further, this study examined older adults' awareness of treatment and management of the disease to improve the quality of life for people diagnosed with PD. Since this disease usually begins between the ages of 50 and 65 and becomes more prevalent as one grows older, this study focused on individuals 50 years of age and older.

Design and Sample

This study utilized a written questionnaire survey that assessed demographic characteristics and knowledge of PD among older adults. The survey method was chosen because it was the most feasible way to gather this

information. The dependent variable of the study was knowledge of PD and the independent variables were age, gender, education, race/ethnicity, and personal connection to an individual with the disease. The research explored the relationship of these variables to knowledge. Approval for the study was obtained from the San Jose State University Committee for the Protection of Human Subjects (see Appendix B).

A sample of convenience was used for the survey. Individuals identified prior to the research as having severe cognitive impairments, mental illness, Alzheimer's disease, or other conditions that would significantly impede their ability to respond appropriately were not asked to participate.

The target population was adults 50 years and older, with the majority residing in Santa Clara County, California. Two hundred sixteen subjects, whose ages ranged from 50 to 98 years, were included in the study. The investigation was limited to adults of least 50 years of age because PD is primarily a disease of older adults. The sample included 75% white subjects and 23% from the racial/ethnic minority groups consisting of Asian Americans, Hispanic Americans, and African Americans. Four subjects (2%) did not respond regarding their race/ ethnicity. Eighty-six percent of the subjects were born in

the United States and 14% named 10 other countries as their country of origin.

The 216 respondents consisted of older adults from Little House Senior Center in San Mateo; Pilgrim Haven, an American Baptist Home of the West in Los Altos; Foothills Congregational Church in Los Altos; The Visiting Nurse Association of Santa Clara County; the Parkinson's Disease Exercise Class in San Jose; the Eastside Neighborhood Center in south San Jose; John XXIII Neighborhood Center in San Jose; Yu-Ai Kai, the Japanese American Senior Center in San Jose; The Parkinson's Institute in Sunnyvale; and a social group in Los Altos.

Twenty-seven subjects diagnosed with PD were included in the study in order to discover if they had more accurate knowledge of the disease than the general public. Ellenberg (1991) noted that prevalence of PD increases with age, especially after the age of 70, and 18 of the 27 sample subjects diagnosed with PD were in the 70 to 79 age group. Originally the intent was to include a larger number of patients with PD in the sample, but this was not achieved due to the difficulty in identifying and locating these subjects. The subjects with PD may not have been representative of all PD patients because they had actively sought outside support for their condition. Forty-nine relatives and 45 close friends diagnosed with PD were known

by the subjects. Fifteen subjects said they had never heard of PD and 47 subjects said they knew little or nothing about the disease.

The convenience sample contained subjects with varying levels of education, and the educational level of the subjects was not controlled. One respondent had no formal education, and others had grade school level, high school level, college level, and graduate school educations.

The subjects in the investigation were predominantly women because there were 150 women and 66 men. Many of the women subjects were wives or caregivers of persons with PD.

Instrument

The survey instrument was designed to obtain information about the demographic characteristics of the subjects and to measure their knowledge about PD (see Appendix C). The demographic items in the Questionnaire for Knowledge of Parkinson's Disease included age, gender, education, race/ethnicity, and whether or not a respondent or his/her family members, friends, or acquaintances had been diagnosed as having PD. The knowledge questions on the Parkinson's Disease Quiz (PDQ) were developed from current literature on PD to cover etiology, epidemiology, diagnosis, symptoms, treatment, prognosis, and management

of the disease. The PDQ was patterned after an Alzheimer's disease quiz by Neal B. Cutler (1985).

The general information section of the questionnaire asked 10 demographic questions and the PDQ consisted of 26 questions measuring knowledge and understanding of PD. These 26 questions were answered with "true," "false," or "don't know." Scores for the quiz were recorded as follows:

1 point = correct answer

0 points = don't know or wrong answer

26 points = maximum score possible

The instrument also included the Parkinson's Disease Quiz Answers. These three printed sheets contained the answers to the 26 questions on the PDQ, and subjects were encouraged to take the answer sheets with them for future reference.

The content validity of the instrument was established by seeking the advice of two experts at The Parkinson's Institute knowledgeable about PD and were familiar with the context of the research. These experts assessed the clarity, accuracy and design of the questions. Changes were incorporated based on their recommendations. The study was pretested on nine randomly chosen subjects and changes were made prior to data collection to improve clarity. The final instrument was written in large English

print so that it could be easily read by older adults who might have failing eyesight.

The internal reliability of this measuring instrument was tested by utilizing coefficient alpha, also known as Cronbach alpha. This test indicated how well the questions on the quiz correlated with the total and measured the variable of interest, i.e. knowledge of PD. The internal reliability was determined to be 89%.

Procedure

Santa Clara County, California, and the surrounding areas have a culturally and ethnically diverse older population that made them desirable for sampling. Therefore, the decision was made to conduct the study in this community and include a diversity of racial and ethnic groups. A number of sites were identified as having potential subjects for the study, and these sites were contacted prior to the investigation. Written permission was requested and received from the City of San Jose Office of Therapeutic Services, where the subjects diagnosed with PD were surveyed (see Appendix D). The other sites in the research gave verbal permission after being telephoned or personally contacted. All subjects were informed both verbally and in writing of the benefits and risks of the

study and were assured that their responses would be confidential. They were required to sign a Participant's Consent Form indicating that they understand the nature of the study and made a voluntary decision to participate (see Appendix E). They were not compensated for their participation, and there was only minimal unidentified risk to the subjects. A few persons refused to participate in the study, perhaps because questions about physical function limitations and illness could have emphasized their personal losses and disabilities (Colsher, 1992). The questionnaire was administered to subjects in a large group, in subgroups, or individually. The most common method for administration was the large group method. The questionnaires were distributed to the large group and allowance was made for the respondents to ask questions. Care was taken to make certain the subjects understood the survey, and they were free to ask questions during the questionnaire response time. When the entire group had finished, printed Parkinson's Disease Quiz Answers were distributed and discussion was held on all of the questions.

If subjects could not read English or if they had some physical limitation that prevented them from completing the quiz, the questionnaire was administered individually or in subgroups. When subjects were unable to read English, the

survey was given with the assistance of volunteer interpreters who were culturally sensitive to the subjects. The questions were read in English or a specific language depending on the preference of the respondents and help was given in writing the answer. When they had completed the quiz, the answers were read to them in the language of their choice. Spanish-speaking volunteer interpreters were utilized at Eastside Neighborhood Center, a Vietnamese-speaking volunteer assisted at John XXIII Neighborhood Center, and a Japanese-speaking volunteer was needed at Yu-Ai Kai.

When a subject had difficulty with the instrument due to tremor, lack of muscle coordination, or other physical limitation, a volunteer was available to assist in completing the questionnaire. When the person had completed the questionnaire, he or she usually was able to join the large group for discussion. These volunteers were needed and available at the Parkinson's Exercise Class, Little House, and Pilgrim Haven.

Questionnaires administered individually or in a subgroup required approximately 15-30 minutes. When the questionnaire was given in a large group, the session lasted approximately 1 to 2 hours. The longer sessions allowed for a group discussion on the PDQ which was

followed by a talk and video on PD presented by the researcher.

Data Analysis

Data collection was completed over a four-month time period from October, 1993, to March, 1994. The 26 questions of the PDQ were analyzed by categorizing the questions into three areas. The first area related to the etiology and epidemiology of the disease and consisted of eight questions. The second category contained 12 questions regarding the symptoms and diagnosis of PD. The six questions in the third area pertained to the treatment, management, and prognosis of PD.

The statistical software used to analyze the data was Epi-Info. The dependent variable was knowledge and the independent variables were age, gender, education, personal connection with PD, and racial/ethnic groups. Descriptive statistics were computed and *t*-test, Analysis of Variance (ANOVA), and Kruskal-Wallis H (equivalent to Chi square) were used for the statistical analyses to examine the differences in the mean score of PD knowledge in the different groups. The findings are presented in the following chapter.

CHAPTER 4

DATA AND RESULTS

Knowledge of Parkinson's disease (PD) was examined among older adults. Five demographic variables that might influence this knowledge and understanding of PD were also explored. Survey findings are presented in this chapter.

Research Findings

Sample Characteristics

The demographic characteristics of the subjects and their connections to PD are presented in Table 1. The sample consisted of 66 men and 150 women. The subjects ranged in age from 50 to 98 years, with a mean age of 69.4 years. The participants were of diverse racial/ethnic backgrounds and had different countries of origin. The subjects' levels of education and familiarity with PD varied. The sample included 18 men and 9 women who were diagnosed as having PD. Subjects were drawn from 10 different sites in Santa Clara County and the surrounding area.

Table 1

Characteristics of the Sample

Description	n	Nearest %
Age of Subjects		
50 to 59 years	53	25%
60 to 69 years	53	24
70 to 79 years	63	29
80 to 89 years	39	18
90 to 99 years	8	4
Gender of Subjects		
Men	66	31%
Women	150	69
Education of Subjects		
No Schooling	1	1%
Grade School	10	5
High School	57	27
College	96	46
Graduate School	47	22
Disease Status of Subjects		
Have PD	27	13%
Don't Have PD	183	85

Continued...

Table 1 Continued

Characteristics of the Sample

Description	n	Nearest %
Race/Ethnicity of Subjects		
White American	162	76%
Asian American	32	15
Hispanic American	16	8
African American	2	1
Birthplace of Subjects		
Canada	2	1%
England	2	1
Hungary	3	1
Japan	1	1
Mexico	9	4
Philippines	1	1
Poland	3	1
Portugal	1	1
Puerto Rico	1	1
United States	185	86
Vietnam	8	4

Continued...

Table 1 Continued

Characteristics of the Sample

Description	n	Nearest %
Location of Subjects		
Little House	39	18%
Foothills Church	33	15
Visiting Nurse Association	33	15
Pilgrim Haven	30	14
PD Exercise Class	22	10
Yu-Ai Kai	21	10
Eastside Neighborhood Center	16	7
Social Group	10	5
John XXIII	8	4
The Parkinson's Institute	4	2
Subjects Heard of PD		
Yes	199	92%
No	15	7

Continued...

Table 1 Continued

Characteristics of the Sample

Description	n	Nearest %
Subjects Familiarity with PD		
Very Familiar	51	24%
Somewhat Familiar	98	45
Not too Familiar	31	14
Not At All Familiar	16	7
No knowledge of PD	13	6
Subjects Know Someone with PD		
Yes	148	69%
No	66	31
People with PD Known by Subjects		
Relative or Close Friend	83	39%
Acquaintance or Other Person	65	30

Participants' Knowledge of PD

The maximum possible score for the Parkinson's Disease Quiz (PDQ) was 26 points and the desirable range was 18 (70%) to 26 points. The actual scores on the PDQ ranged from 0 to 25 points. The average or mean score was 15.4 points and the median score was 17. No one received a perfect score, 1 subject received a score of 25 points, and 9 subjects received a score of 0. If a subject received a score of 20 or more, they were considered to have excellent knowledge about PD. A score of 14-19 indicated good knowledge, 7-13 points indicated fair knowledge, and 6 and below indicated poor knowledge of PD (see Table 2).

The PDQ data were analyzed by categorizing the questions into three areas. The first area related to the etiology and epidemiology of PD. The second category concerned symptoms and diagnosis of the disease. The last area pertained to treatment, management, and prognosis.

The first category of etiology and epidemiology included 8 questions with a maximum possible score of 8 points. Actual scores attained in this area ranged from 0 to 8 and the mean score was 3.95 points. The desirable range for this category was 5 to 8 points. Fourteen subjects scored 0 in the area and 4 scored 8 points. An analysis of these 8 questions showed that only 3 of these questions were answered correctly by 50% or more of the

Table 2

Distribution of Knowledge Scores N = 216

Scores	Frequency	Percent
0-6	18	8%
7-13	47	22%
14-19	95	44%
20-26	56	26%
Total	216	100%

Note: Percent rounded to the nearest whole number.

Maximum score possible = 26 points

Mean = 15.4 points Actual score range = 0 - 25

Desirable range = 18 - 26 points

respondents. One hundred ninety one subjects (88%) knew that PD is not contagious; 182 participants (84%) knew that the disease is not a normal part of growing old; and 140 subjects (65%) knew that PD is not a rare disease (see Table 3).

There were 12 questions in the second category of symptoms and diagnosis, the total number of points possible was 12. The actual scores ranged from 0 to 11, with 12 subjects having a score of 0 points and 24 subjects receiving 11 points. The mean score was 7.51 and the desirable range was 8 to 12 points. Ten of these questions were answered correctly by 50% or more of the respondents. Participants performed poorly on 2 of the questions; only 34 subjects (16%) knew that tremors of the voice, head, and hands are not definite signs of PD, and only 48 subjects (22%) knew that PD cannot be diagnosed by a blood test (see Table 4).

The third category on treatment, management, and prognosis of PD contained 6 questions, with 6 being the total points possible. The scores ranged from 0 to 6 points, with 16 subjects (7.4%) receiving 0 points and 47 subjects (22%) receiving maximum scores. The mean score was 3.94 and the desirable range was 4 to 6 points. Four questions in this category were answered correctly by 50% or more of the subjects. Only 103 subjects (47%) were

Table 3

Knowledge of Parkinson's Disease N = 216

Etiology and Epidemiology Questions	Responses and Percent Right	Wrong	Don't Know
PD can be contagious. (F)	191(88%)	1(01%)	24(11%)
PD is a normal part of growing old. (F)	182(84%)	8(04%)	26(12%)
Parkinson's disease is a rare disease. (F)	140(65%)	33(15%)	43(20%)
PD symptoms uncommon before the age of 50. (T)	99(46%)	48(22%)	69(32%)
Toxic substances may cause conditions like PD. (T)	97(45%)	12(06%)	107(50%)
A man is more likely to have PD than a woman. (F)	63(29%)	57(27%)	96(44%)
PD may be inherited. (T)	54(25%)	54(25%)	108(50%)
More PD in Whites than other races. (F)	28(13%)	49(23%)	139(64%)

Note: T = True F = False

Maximum score possible = 8 Score range = 0 - 8

Mean = 3.95 Desirable range = 5 - 8 points

Table 4

Knowledge of Parkinson's Disease N = 216

Symptoms and Diagnosis Questions	Responses and Percent Right	Wrong	Don't Know
People with PD take longer to dress. (T)	179(83%)	5(2%)	32(15%)
Poor balance and falls are common with PD. (T)	177(82%)	6(3%)	33(15%)
Speech is sometimes affected when one has PD. (T)	166(77%)	10(05%)	40(18%)
Difficulty standing from sitting occurs with PD. (T)	164(76%)	6(03%)	46(21%)
PD causes physical and mental decline. (T)	159(74%)	18(08%)	39(18%)
The tremor of PD occurs in nonmoving limbs. (T)	152(71%)	3(01%)	61(28%)
Handwriting often affected with PD. (T)	151(70%)	3(01%)	62(29%)
PD causes stooped posture and shuffling steps. (T)	148(69%)	19(09%)	49(23%)
PD patients drool and and take longer to eat. (T)	147(68%)	6(03%)	63(29%)
PD causes stiff muscles that won't relax normally. (T)	131(60%)	6(03%)	79(37%)
PD can be diagnosed by a blood test. (F)	48(22%)	27(13%)	141(65%)
Voice, head, and hand tremors are definite signs of PD. (F)	34(16%)	136(63%)	46(21%)

Note: T = True F = False Maximum score Possible = 12

Score Range = 0-11 Mean = 7.51 Desirable range = 8-12

aware that Medicare will not pay for nursing home coverage and medicines for PD, and only 80 (37%) knew that experimental brain implants of dopamine-producing fetal neurons can improve disease conditions (see Table 5).

Demographic Factors and PD Knowledge

The second objective of this study was to explore the relationship of various demographic factors to knowledge of PD by older adults. The five hypotheses generated for the study were examined.

Hypothesis 1:

It was hypothesized that older adults who have been diagnosed as having PD or have a family member or close friend with the disease have more knowledge of PD than those respondents who have no personal connection with the disease.

Twenty seven individuals in the investigation had PD. The difference in the mean scores of PD knowledge and having and not having the disease was examined. It was expected that having the disease would make respondents more knowledgeable. If a person has a disease that affects their life, they usually make an effort to learn all they can about the disease. As expected, subjects diagnosed with PD were found to have higher score than subjects who

Table 5

Knowledge of Parkinson's Disease N = 216

Treatment, Prognosis and Management Questions	Responses and Percent Right	Wrong	Don't Know
Families and persons with PD have support groups. (T)	171(79%)	2(01%)	43(20%)
PT, OT, and ST can help manage symptoms of PD. (T)	168(78%)	7(03%)	41(19%)
Treatment with drugs can retard PD progression. (T)	167(77%)	7(03%)	42(20%)
There is a cure for Parkinson's disease. (F)	161(74%)	4(02%)	51(24%)
Medicare covers all PD meds and nursing home expenses. (F)	103(48%)	12(06%)	101(47%)
Experimental brain implants may improve PD. (T)	80(37%)	16(07%)	120(56%)

Note: T = True F = False

Maximum score possible = 6 Score Range = 0 - 6

Mean = 3.94 Desirable range = 4 - 6 points

did not have the disease. The mean score of the subjects without PD was 15.14, and the median score was 16, whereas these scores for the diagnosed respondents were 19.33 and 21. The results of this test were statistically significant with Kruskal-Wallis H (equivalent to Chi square $_{(1, N = 210)}$) = 16.46, $p < .001$ (see Table 6).

Participants were asked if they had ever heard of PD, and if so, how familiar they were with the disease. According to the research findings, the subjects who stated they were very familiar with PD had more knowledge about the disease and scored the highest on the quiz. There was a direct relationship between knowledge and familiarity with the disease with Kruskal-Wallis H (equivalent to Chi square$_{(4, N = 209)}$) = 75.25, $p < .001$ (see Table 7).

One hundred forty eight respondents stated they knew someone with PD, and 66 said they did not know anyone with the disease. The researcher examined whether knowing someone with the disease would be associated with a significantly higher score on the PDQ. It was anticipated that knowledge would be greater when a person knows someone with PD, because they would be more informed about the disease. The data bore this out in that the effect of knowing someone on the mean knowledge scores revealed a significant difference with Kruskal-Wallis H (equivalent to Chi square$_{(1, N = 214)}$) = 23.34, $p < .001$ (see Table 8).

Table 6

Relationship of Having Parkinson's Disease and Knowledge of Parkinson's Disease N = 210

Have PD	n	Mean	SD	x^2
Yes	27	19.33	4.09	16.46*
No	183	15.14	5.84	

Note: *$p < .001$

Six persons did not respond.

Table 7

Relationship Between Familiarity and Knowledge of Parkinson's Disease N = 209

Familiar	n	Mean	SD	x^2
Very	51	20.16	3.06	75.25*
Somewhat	98	15.33	4.87	
Not too	31	15.55	4.02	
Not at all	16	8.44	5.64	
Never heard of PD	13	8.08	8.20	

Note: *$p < .001$

There were 7 subjects who did not respond.

Table 8

Relationship of Knowing Someone with Parkinson's Disease and Knowledge of the Disease N = 214

Know PD	n	Mean	SD	x^2
Yes	148	17.01	4.59	23.34*
No	66	12.21	6.90	

Note: *p< .001

There were 2 subjects who did not respond.

The researcher further examined whether having a close friend or relative with PD would make a person more knowledgeable about the disease. Eighty three subjects (39%) had a relative or close friend with the disease and 65 (30%) had an acquaintance or other association with PD. It was anticipated that the closer the association one has with a person with PD, the more one would know about the disease. However this was not supported with $F_{(1,146)} = .214$, $p > .05$ (see Table 9).

Hypothesis 2:

The second hypothesis was that older adults with more formal education have more accurate knowledge of PD than those with less education. The respondents had varying levels of education. A one-way ANOVA was performed to compare the knowledge of Parkinson's disease with the amount of education the subjects had received. The scores were proportionately higher among the participants with more formal education. The comparison statistics revealed a significant difference among the means with $F_{(4,206)} = 4.033$, $p < .01$ (see Table 10). Years of education are positively related with more accurate knowledge and understanding about PD. However, differences in mean scores were relatively small.

Table 9

Relationship of Who Know with Parkinson's Disease and Knowledge N = 148

Who	n	Mean	SD	F
Relative/Close Friend	83	17.16	4.50	.214*
Acquaintance/Other	65	16.82	4.74	

Note: *p >.05

Table 10

Relationship of Education and Knowledge of Parkinson's Disease N = 211

School	n	Mean	SD	F
No school	1	0.00	0.00	4.033*
Grade	10	11.10	6.54	
High	57	15.37	6.38	
College	96	16.22	4.60	
Graduate	47	16.30	6.26	
	211			

Note: *p < .01

There were 5 subjects who did not respond.

Hypothesis 3:

It was hypothesized tha white older adults have more knowledge of PD than older adults from other racial/ethnic groups. There were 50 subjects from the minority groups. Two African Americans participated in the the survey, and because of this low representation, they were excluded from this analysis. The data collected on the groups indicated that 54% of the Hispanic American participants and 75% of the Asian Americans had heard of PD, as compared to 96% of the White Americans (see Table 11). These percentages and the data analysis might not reflect the true picture because of the limited number of subjects in the minority groups.

It was anticipated that White Americans would have more knowledge of PD than the minority groups but the analysis indicated there is little difference among these groups regarding their knowledge scores on the PDQ. The data revealed that the knowledge of PD is the same for the racial/ethnic groups with $F_{(2,207)} = 2.918$, $p > .05$ (see Table 12).

There were 31 foreign born individuals in the study. Though PD is a universally known disease, it was anticipated that knowledge about the disease would be the less for the 31 foreign born subjects than for individuals born in the U.S. Analysis of the data found that foreign

Table 11

Racial/Ethnic Groups Heard of Parkinson's Disease N = 210

Groups	Yes	No
White American	156	6
Asian American	26	6
Hispanic American	11	5
	193	17

Note: Four subjects did not respond and 2 African Americans were excluded from the study.

Table 12

Relationship of Racial/Ethnic Groups and Knowledge of Parkinson's Disease N = 210

Groups	n	Mean	SD	F
White	162	16.14	5.43	2.918*
Asian	32	13.88	6.91	
Hispanic	16	13.75	7.14	

Note: *p >.05

Four subjects did not respond and 2 African Americans were excluded from the study.

born individuals did know less about PD than those individuals born in the U.S. The analysis is significant with $F_{(1, 213)} = 20.343$, $p < .001$ (see Table 13).

Hypothesis 4:

The fourth hypothesis was that older women know more about PD than older men. The rationale for this hypothesis was that women live longer than men and traditionally are more likely to be caregivers. It was anticipated that this longevity and caregiver role would provide women more opportunity to gain knowledge of PD. There were 150 older women and 66 older men in the survey. The PDQ data indicated that though there was not a large difference in the mean scores, the knowledge and understanding of PD among women is greater than that of men with $F_{(1,214)} = 3.729$, $p < .05$ (see Table 14).

Hypothesis 5:

The last hypothesis was that older adults have more knowledge about PD than younger adults. Since the disease is more prevalent as one grows older, it was expected that older adult respondents would have more information and knowledge about the disease. It was anticipated the older adults would have friends of similar age with the disease or they themselves may be diagnosed with PD.

The mean age of the 216 participants was 69.4 years and the largest number of the participants, 63 (29%), were

Table 13

Relationship of US and Foreign Born and Knowledge of Parkinson's Disease N = 216

Groups	n	Mean	SD	x^2
US Born	185	16.12	5.36	8.19*
Foreign Born	31	12.86	7.26	

Note: *$p < .01$

Table 14

Relationship between Gender and Knowledge of Parkinson's Disease N = 216

Gender	n	Mean	SD	F
Men	66	14.41	6.54	3.73*
Women	150	16.06	5.43	

Note: *$p \leq .05$

in the 70 to 79 years age bracket (see Table 1). The survey data revealed that there was little difference among the various age groups regarding their knowledge about PD. The mean scores were more or less the same regardless of age, even though the disease is more prevalent in older age. The results of the analysis indicated that there is insufficient evidence to support the hypothesis when Kruskal-Wallis H (equivalent to Chi square$_{(4,\ N\ =\ 216)}$)= 6.28, $p > .05$. The knowledge of PD is the same for all age groups (see Table 15).

Summary

The basic research question was as follows: What do older adults know about the etiology, epidemiology, symptoms, diagnosis, prognosis, treatment and management of Parkinson's disease? The study found that older adults in Santa Clara County, California and the surrounding area do not have adequate knowledge about the etiology, epidemiology, symptoms diagnosis, prognosis, treatment, and management of PD. Relative to the hypothesis it was found that significant relationships exists between certain demographic characteristics and knowledge of the disease.

Table 15

Relationship Between Age and Knowledge of Parkinson's Disease N = 216

Age	n	Mean	SD	x^2
50-59	53	16.51	5.66	6.276*
60-79	53	15.60	6.38	
70-79	60	15.22	6.62	
80-89	39	14.72	4.04	
90-99	8	15.63	3.74	

Note: *p >.05

CHAPTER 5

DISCUSSION AND RECOMMENDATIONS

The incidence of Parkinson's disease (PD) has remained relatively constant for several decades, but it is expected to increase significantly as the United States population ages (Parkinson NPF Report, 1994). Therefore, it is important for older Americans to know about PD because they need to be able to recognize this disease and understand it's prognosis and the ultimate impact it could have on their lives. This investigation, which measured PD knowledge by survey questionnaires, found that older Americans lack knowledge about this neurodegenerative condition. Further, the study indicated that significant relationships exist among gender, education, and personal association with PD and knowledge of the disease.

Questionnaire Results

Parkinson's Disease Knowledge

There were 26 knowledge questions on the Parkinson's Disease Quiz (PDQ). The data revealed that 100 subjects (46%) answered 18 questions (70%) or more correctly.

Forty-nine percent of the total responses in the area of etiology and epidemiology were correct answers, 64% correct responses were given in the symptoms and diagnosis category, and 66% correct answers were given in the category for PD awareness, treatment and management. Sixty percent of the subjects' total responses on the 26 questions were correct answers.

Knowledge about PD was examined by analysis of the responses to the following questions. Eighty-seven percent did not realize that the disease affects all races of mankind equally all over the world, and 78% did not understood that PD cannot be diagnosed by a blood test. Seventy-five percent of the subjects did not realize that the disease may be an inherited disease while 71% of the subjects did not know that PD affects men and women in equal proportions. Sixty-three percent had no knowledge that transplanting fetal neurons into adult brains can improve PD symptoms.

Fewer than half of the subjects were able to correctly answer questions about symptoms of PD appearing before the age of 50, Medicare coverage for medications and nursing home care for PD patients, and exposure to toxic substances resulting in conditions similar to PD. Close to 40% of the respondents did not know that people with PD have abnormally stiff muscles and this is a primary symptom.

One question that only 16% of the participants answered correctly stated that tremors in the voice, head, and hands are definite signs of PD. This question was confusing to the majority of the respondents. It is possible to have these types of tremors in PD, but they are not a definite sign of PD and can actually be a sign of essential tremor. The misleading word was "definite." This question should be reworded for clarity or eliminated from the PDQ. Another confusing question regarding tremor stated that tremor of PD occurs in the hands and sometimes the feet of nonmoving limbs. Although it was answered correctly by 70% of the subjects, some participants were puzzled by the question. It should be reworded to read: "PD tremor, referred to as resting tremor, generally affects limbs that are not in motion." Also the question stating that people with PD walk with stooped posture and shuffling gait should be reworded to read that "most people..." because most, but not all, people with PD have these symptoms.

The prognosis of PD was not directly addressed in the PDQ. The original draft contained a prognosis question asking if PD is a fatal disease. The answer is false: it is not a fatal disease, although considerably disabling (National Parkinson Foundation, 1993). The question was eliminated from the quiz on the recommendation of a PD

expert who felt the question might cause anxiety in persons with PD who would be part of the study. The question on the PDQ that asked if there is a cure for PD indirectly addressed prognosis.

Factors Correlated with Knowledge

The following factors were analyzed to determine their correlation with older adults' knowledge about PD. First, the study investigated whether being diagnosed with PD would show a relationship with subjects' knowledge about the disease. Using persons diagnosed with PD and persons without PD permitted comparison of the two groups' knowledge of the disease. Twenty-seven (13%) of the 216 respondents had PD. Although the number of subjects diagnosed with PD was fewer than initially anticipated, this 13% was much larger than the reported incidence which is 1% of persons over the age of 55 (Parkinson NPF Report, 1994). Eighteen of those diagnosed with PD were men and 9 were women. This ratio of men to women varied from most studies which have found that there is no sex difference in the incidence of PD (Tanner, 1992). The sample was small and not representative of the total population, which could explain this ratio in the study.

The data from those who were diagnosed with PD, as distinguished from those who did not have the disease, revealed that knowledge was greater for those with PD. As previously stated, this was anticipated; it was assumed that if a person is diagnosed with a disease, he or she often learn all they can about the disease. Also, as expected, the data affirmed that the more familiar a person is with PD, the more knowledge they will have about the disease. Sixty nine per cent of the participants knew someone with PD, and the statistical data revealed that if the subjects knew someone with the disease, they were more informed. This agreed with the knowledge studies on Alzheimer's disease that found that knowing someone with the disease led to greater knowledge of that disease (Cutler, 1987; Price et al., 1986). Dent and Goulston (1982) also found that those knowing someone with cancer scored better than those with no personal experience with the disease.

Having a close friend or relative with PD, compared to knowing only an acquaintance or other person with the disease, did not reveal a significant difference in knowledge of the disease. This disagreed with Price et al. (1986) and Cutler (1987) who reported that respondents who had a friend or relative with the Alzheimer's disease

scored significantly higher on the Alzheimer's disease knowledge test than subjects who knew only acquaintances.

In reviewing the relationship of PD knowledge for the 83 subjects who had a friend or relative with the disease and for the 65 subjects who knew an acquaintance or other person with PD, the reasons for this outcome was obvious. The question "Who do you know with Parkinson's disease?" was not clearly written. Some thought "other person" meant a husband or wife since they did not consider their spouse to be a relative, as was expected by the researcher. Also the subjects from the medical profession at the Visiting Nurse Association considered "other person" to mean patients or clients they treated. Therefore, knowing a spouse or a patient with PD would give one more knowledge of the disease and could skew the results. The distinction of "other" needs to be clarified in the survey questions.

Another factor tested for association with knowledge of PD was the educational level of the subjects. The analysis revealed that years of education correlated positively with increased knowledge of PD. Data from the knowledge studies of the literature review also indicated that education had a positive association with disease knowledge (Berman & Wanderman, 1991; Cutler, 1987; Dent & Goulston, 1982; DiClemente, Boyer, & Morales, 1988;

LeBlanc, 1993; McCraig, Hardy, & Winn, 1991; Michielutte & Diseker, 1982; Price et al., 1986).

A third factor associated with the knowledge of PD was the race/ethnicity of the respondents. Fifty minority subjects (23%) participated in the research. The analysis did not indicate that White Americans had more knowledge about PD than the racial/ethnic minority groups. The results may be skewed due to the small number of minority subjects. This result disagreed with the knowledge studies in the literature review that found that the minority groups had less knowledge of cancer, AIDS, and HIV than white participants (Berman & Wanderman, 1991; Craig et al. 1991; DiClemente et al. 1988; LeBlanc, 1993; Michielutte & Diseker, 1982).

However, the analysis did disclose that foreign-born subjects had less knowledge of PD than those born in the U.S. Thirteen of the 15 subjects who stated that they had never heard of PD were foreign born. There is a possibility that, although PD is a universally known disease, the foreign born subjects (many of whom spoke only their native tongue) may have known the disease by a different name, resulting in an apparent lack of knowledge of PD. This analysis agreed with Dent and Goulston (1982) who found in their study of cancer knowledge in Australia that subjects whose birthplace was an English-speaking

country had significantly higher scores on their cancer quiz than subjects from other countries.

A fourth factor associated with knowledge of PD was the gender of the respondents. It appeared to the researcher that the women were more willing to participate in the investigation and more interested in learning about PD. There were 150 women (69%) as compared to 66 men. The analysis revealed that women have more knowledge of PD than men. The data from other knowledge studies also found that females had more awareness and information about various conditions than the male subjects (Cutler, 1987; Dent & Goulston, 1982; LeBlanc, 1993; Michielutte & Diseker, 1982).

The last factor tested for association with knowledge about PD is age. The rationale for surveying subjects 50 years of age and older was that PD is primarily a disease of the elderly with the average age of onset approximately 61 years (Duvoisin, 1991). It was assumed that the older the adults, the more knowledge they would have about the disease because they might have the disease or they could have older friends with PD. However, the results of this survey indicated there was little difference among the various age groups about knowledge of PD.

The knowledge studies in the literature reviewed showed varying results relating to the correlation between

age and knowledge. Cutler (1987) found age made little difference in knowledge of Alzheimer's disease. McCraig et al. (1991) found in their study on knowledge about AIDS and HIV that subjects 50 years and older had lower scores than the younger subjects. Michielutte and Diseker (1982) found that their older participants also had less knowledge of cancer perhaps due to less education, and older adults in the study by LeBlanc (1993) had slightly lower levels of HIV-related knowledge. Dent and Goulston (1981) found that subjects 40 years and older scored higher on cancer knowledge test than those below 40 years.

Procedure Evaluation and Suggestions

The survey questionnaires were given in large groups, subgroups, and individually. There was more open discussion about PD and more participation in the questionnaire in the large group presentations. Only a few older adults refused to participate in the survey or were reluctant to answer the questions on the PDQ. This may have been due to denial of the disease or because they were intimidated by the PDQ. Refusal to respond also may have occurred because answering the questions might reveal the subject's depth of ignorance about the disease (Dent & Goulston, 1982). Care was taken to make sure subjects felt

comfortable taking the questionnaire and were aware that they would be gaining knowledge about PD from participating in the investigation.

When the subjects had completed the questionnaire, they were given information sheets with printed answers to the PDQ questions, which were then explained and discussed individually or in groups (see Appendix E). Participants were encouraged to keep the answer sheet for future reference. If time permitted, the subjects in the large groups were shown an informative video entitled "Coming to Terms with Parkinson's Disease" (Sandoz Pharmaceutical, 1993). The video was well received and added useful information for the older adults.

The participants benefitted from this study because it provided knowledge and awareness of PD. It gave useful information about PD to subjects who may be at risk of developing the disease or encountering PD in a significant other. Also subjects diagnosed with PD and health care providers and caregivers who participated in the study became more knowledgeable about current facts and treatment of the disease.

Information about various diseases and conditions is important for older adults. Because of the slow, progressive nature of PD, older adults may not seek professional advice until their condition is advanced. If

they do not have accurate knowledge of PD, they may attribute their symptoms of the disease to the aging process. Seeking professional advice can lead to an earlier diagnosis of the disease. If a diagnosis is made while a person is still mobile and alert, more successful treatment and management of the disease may be accomplished.

The National Parkinson Foundation (1993) proclaims that a diagnosis of PD is a serious event in an individual's life. How these individuals interpret and understand the information about the disease is extremely important. Misconceptions and misinformation are confusing and misleading. Often words like "incurable" and "progressive" cause unnecessary and increased anxiety and fear. Individuals need to know that PD progression varies with different people and many PD sufferers continue to enjoy life for a long time. Accurate information can help those diagnosed with PD learn how to cope with the disease physically and mentally. "Those who accept the condition and seek information are better able to plan their existence with it intelligently" (National Parkinson Foundation, 1993, p. 15).

The results of this investigation will be shared with health care professionals and policy makers. This study can be more carefully designed to sample a larger and more

representative racial/ethnic and educational balance. From a more complete study, the statistical information, implications, and recommendations can be used to design and develop culturally and ethnically appropriate and accurate informational materials and programs about PD for older adults.

Recommendations

This investigation produced evidence that there is a need to improve knowledge of PD among older adults. Both the public and health care professionals would benefit from increased knowledge about this disease. One study that assessed the knowledge of Alzheimer's disease noted that more effort should be made to increase the quality and quantity of information about the disease in the mass media (Price et al., 1986). Cutler (1987) also reported the need to further consider the quality of public information about diseases.

Information should be made available at locations such as senior centers, retirement homes, and doctor's offices. This information should be in the native language of the older adults in places like Eastside Neighborhood Center, John XXIII Neighborhood Center, and Yu-Ai Kai where minorities are present. Some cultural practices often limit or preclude motivation to access information

regarding Western medical care, and these practices need to be acknowledged and addressed so that the symptoms of PD are recognized. Older adults of all races need information about PD that is relevant and appropriate for them.

There are many avenues by which information can be disseminated. Some public media strategies consist of newspapers, television, radio, pamphlets, and posters. Accurately informed support groups, workshops, and programs could be used to increase awareness of PD.

It is recommended that a larger study with better sampling and more careful questionnaire design be conducted on other older adult populations to expand and verify the findings of this study. It is also recommended that an investigation be conducted to determine knowledge that young adults ages 20 to 50 hold about PD. This age group includes the "baby boomers" born 1946 to 1964. Knowledge of the disease is important for them because they may become caregivers for the aging population and are also at risk to develop the disease. Knowledge of this disease will enhance their caregiving potential and also increase their knowledge of the disease should they or their friends become afflicted with the disease as they become older.

Parkinson's disease can be a frightening disease not only to those who are diagnosed but also to their families, friends, and caregivers. Knowledge can diffuse that fear.

Scientists and physicians are continually learning more about the disease and discovering ways to slow or even change the course of the disease. Accurate knowledge and understanding about this debilitating disease is important for older adults and the total population to enable earlier diagnosis and better care for longer and more productive lives. Improving the knowledge base about PD is necessary because PD is a common disease of the present and is expected to increase significantly in the future as life expectancy increases and the population ages.

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APPENDICES

APPENDIX A

CONSENT TO USE ILLUSTRATION

HARRIET R. GREENFIELD MEDICAL ILLUSTRATOR

ANNE OLIVER
2216 DEODARA DRIVE
LOS ALTOS, CA.
94024

Dear ANNE

In response to your request to reuse my illustration entitled PARKINSON'S DISEASE " that apperaed in HARVARD HEALTHLTR on MAY/JUNE 1993. I am sending you the following forms. There is X charge ~~and specific conditions~~ for the onetime reuse of this illustration. ~~Please complete and send both signed forms to me. I will countersign and return one to you for your files.~~

Do not hestitate to call me at 617-969-3810 with any questions. Thank you for your interest.

Sincerely yours,

Harriet R Greenfield.

Harriet R. Greenfield

381 highland street newton,ma 02160 phone 617 969 3810 fax 617 969 8803

APPENDIX B

APPROVAL FROM THE HUMAN SUBJECTS-INSTITUTIONAL REVIEW BOARD

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

Office of the Academic Vice President • Associate Academic Vice President • Graduate Studies and Research
One Washington Square • San Jose California 95192-0025 • 408 924-2480

To: Ann P. Oliver
2216 Deodara Dr.
Los Altos, CA 94024

From: Serena W. Stanford Serena W. Stanford
AAVP, Graduate Studies and Research

Date: October 13, 1993

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"Knowledge of Parkinson's disease: A study of older adults in Santa Clara County"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at anytime. Further, a subject's participation, refusal to participate or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.
If you have questions, please contact me at 408-924-2480.

Approval is given for 1 year from date of letter.

APPENDIX C

INSTRUMENT

Questionnaire for Knowledge of Parkinson's Disease

Parkinson's Disease Quiz (PDQ)

Parkinson's Disease Quiz (PDQ) Answers

Questionnaire for Knowledge of Parkinson's Disease

General Information

1. Today's date: _____
2. Gender: _____ male _____ female
3. Birth date: _____
4. Racial/Ethnic group:
   ____ Hispanic ____ African American
   ____ White ____ Asian American
   ____ Other
5. How many years of schooling have you completed:
   ____ grade school ____ high school
   ____ college ____ graduate school
6. In what country were you born: _____
7. If not born in the U.S., when did you come to the United States:
   _____ year
8. Have you heard of Parkinson's disease:
   ____ yes ____ no
   If yes, how familiar: ____ very ____ somewhat
   ____ not too ____ not at all
9. Do you have Parkinson's disease:
   ____ yes ____ no
10. Do you know anyone with Parkinson's disease:
    ____ yes ____ no
    If yes, who are they: ____ relative ____ close friend
    ____ acquaintance ____ other

Parkinson's Disease Quiz (PDQ)

The following questions are to be answered with **TRUE**, **FALSE**, or ***DON'T KNOW***. Please mark the answer you think is correct.

T	F	DK	1. Parkinson's disease can be contagious.
T	F	DK	2. Parkinson's disease is a normal part of getting older, like grey hair or wrinkles.
T	F	DK	3. A person with Parkinson's disease can experience both physical and mental decline.
T	F	DK	4. A man is more likely to develop Parkinson's disease than a woman.
T	F	DK	5. Treatment with certain drugs can retard the progression of Parkinson's disease.
T	F	DK	6. Often the handwriting is small, jerky, or cramped when one has Parkinson's disease.
T	F	DK	7. There is a higher rate of Parkinson's disease in Whites than other races.
T	F	DK	8. It is uncommon for symptoms of Parkinson's disease to appear before the age of 50.
T	F	DK	9. Difficulty in standing from a sitting position often occurs in Parkinson's disease.
T	F	DK	10. There are support groups for families and persons with Parkinson's disease.
T	F	DK	11. People with Parkinson's disease walk with a stooped posture and shuffling steps.

T	F	DK	12. Parkinson's disease can be diagnosed by a blood test.
T	F	DK	13. All nursing home expenses and medications for Parkinson's disease patients are covered by Medicare.
T	F	DK	14. Exposures to toxic substances may result in a condition similar to Parkinson's disease.
T	F	DK	15. Poor balance and falls are common with Parkinson's disease.
T	F	DK	16. People with Parkinson's disease usually take much longer to dress than others their age.
T	F	DK	17. Speech is sometimes affected when one has Parkinson's disease.
T	F	DK	18. Parkinson's disease may be an inherited disease.
T	F	DK	19. There is a cure for Parkinson's disease.
T	F	DK	20. Physical, occupational, and speech therapy can help a person manage the symptoms of Parkinson's disease.
T	F	DK	21. People with Parkinson's disease have stiff muscles that won't relax normally.
T	F	DK	22. Sometimes Parkinson's disease patients drool and take much longer to eat than other people their age.
T	F	DK	23. Tremors in the voice, head, and hands are definite signs of Parkinson's disease.
T	F	DK	24. People with Parkinson's disease have had experimental brain implants that improves their condition.

T F DK 25. The tremor of Parkinson's disease occurs in the hands, and sometimes the feet of nonmoving limbs.

T F DK 26. Parkinson's disease is a rare disease.

Parkinson's Disease Quiz Answers

1. Parkinson's disease can be contagious.

   False. There is no evidence that the disease is contagious. Many attempts to find an infectious agent in Parkinson's disease have failed.

2. Parkinson's disease is a normal part of getting older, like grey hair or wrinkles.

   False. Parkinson's disease is associated with older adults, but it is a disease and not the inevitable consequence of aging.

3. A person with Parkinson's disease can experience both physical and mental decline.

   True. Physical decline occurs first and is more obvious and severe in the progression of the disease, but estimates suggest that dementia, or the decline in thinking abilities, occurs in between 12 to 25% of people with PD.

4. A man is more likely to develop Parkinson's disease than a woman.

   False. Most studies indicate no difference in the incidence of the disease in men versus women.

5. Treatment with certain drugs can retard the progression of Parkinson's disease.

   True. There is evidence that treatment with certain drugs may slow progression of the disease if used in the early stages of newly diagnosed cases.

6. Often the handwriting is small, jerky, or cramped when one has Parkinson's disease.

   True. Characteristic changes in handwriting occur in PD: the letters are well formed but get progressively smaller until they may become difficult to read. Also tremor may be evident in the writing with very small squiggles in the letters.

7. There is a higher rate of Parkinson's disease in Whites than other races.

   False. The disease affects all races of mankind equally all over the world.

8. It is uncommon for symptoms of Parkinson's disease to appear before the age of 50.

   True. It is difficult to date exact onset because initial symptoms are subtle and progression is so gradual. It is uncommon to have PD before age 50, but approximately 25% do have symptoms before this age. The average age of onset is 61, and diagnosis is rare before the age of 30.

9. Difficulty in standing from a sitting position often occurs in Parkinson's disease.

   True. Standing from a sitting position is often difficult due to rigidity and slowness in muscle movement. Other symptoms causing difficulty are a delay in starting movements and an arrest of ongoing movements called "freezing".

10. There are support groups for families and persons with Parkinson's disease.

    True. There are Parkinson's Support Groups in many locations that can be of tremendous help to patients and their families. Members exchange ideas and share advise on means of coping with practical problems.

11. People with Parkinson's disease walk with a stooped posture and shuffling steps.

    True. Parkinson patients have a tendency to bend their trunk forward while walking and have short and shuffling steps.

12. Parkinson's disease can be diagnosed by a blood test.

    False. Laboratory tests presently have little value in identifying Parkinson's disease. Blood tests can be used to rule out or identify other conditions.

13. All nursing home expenses and medications for Parkinson's disease patients are covered by Medicare.

    False. Medicare presently pays only for short-term acute care in nursing homes and not for long-term care. Medicare does not cover medication expenses.

14. Exposures to toxic substances may result in a condition similar to Parkinson's disease.

    True. There is a strong possibility that environmental substances cause a condition like Parkinson's disease. Research is being done to study this possibility.

15. Poor balance and falls are common with Parkinson's disease.

    True. Parkinson's patients often have poor balance and may not be able to react to abrupt changes in position. This contributes to frequent falls.

16. People with Parkinson's disease usually take much longer to dress than others their age.

    True. This is due to movement delay, slowness of muscle movement, and increased muscle stiffness. In addition fine motor tasks like buttoning a shirt or tying shoelaces may be difficult because of tremor and incoordination of movement.

17. Speech is sometimes affected when one has Parkinson's disease.

    True. The first change is usually a tendency to speak softly. Other characteristics are a monotone and rapid speech. All of the changes of speech can be improved by effective drug therapy.

18. Parkinson's disease may be an inherited disease.

    True. Theories about genetic cause hold credence and are being researched. It may be inherited, but there is no consistent evidence to prove the genetic cause. Some cases of Parkinson's disease are familial and some are not.

19. There is a cure for Parkinson's disease.

False. At present there is no cure for Parkinson's disease, so treatments relieve symptoms and keep the patient functional as long as possible.

20. Physical, occupational, and speech therapy can help a person manage the symptoms of Parkinson's disease.

True. Mobility and independence are the major objectives in the management of persons with PD. To achieve these objectives, drug therapy must be augmented by suitable programs of physical, occupation, and speech therapy.

21. People with Parkinson's disease have stiff muscles that won't relax normally.

True. There is tightness and firmness in the muscles that won't relax. This can cause not only a sense of stiffness but also can cause a tired aching feeling, persistent soreness, pain, or cramping.

22. Sometimes Parkinson's disease patients drool and take much longer to eat than other people their age.

True. Eating may be slower because the automatic act of swallowing is decreased and the throat muscles action is slowed. This can result in the pooling of saliva in the mouth and throat causing drooling.

23. Tremors in the voice, head, and hands are definite signs of Parkinson's disease.

False. It could be PD, but chances are the tremors are essential tremor (ET). ET is the most prevalent movement disorder in the U.S. Although there is no cure, it is treatable. It isn't life threatening; it rarely has any other symptoms; and it won't lead to Parkinson's disease.

24. People with Parkinson's disease have had experimental brain implants that improves their condition.

True. Parkinson's disease occurs when more than 80% of the dopamine producing cells of the brain are lost. Surgical attempts to replace these lost cells are being done by transplanting dopamine producing cells into the brain. This is experimental and controversial surgery and has yet to be proven totally successful.

25. The tremor of Parkinson's disease occurs in the hands, and sometimes the feet of nonmoving limbs.

True. Resting tremor is the most obvious and familiar symptom of PD. This uncontrollable tremor or shaking generally occurs when the affected hands, feet or other affected areas are at rest.

26. Parkinson's disease is a rare disease.

False. Parkinson's disease is the second most common neurodegenerative disease of older adults surpassed only by Alzheimer's disease. It is believed to affect about 1 out of every 100 people over the age of 60 and has become one of the most common ailments in the United States.

Questionnaire and quiz
designed by the researcher
Ann P. Oliver
October 1993

APPENDIX D

CONSENT FOR STUDY AT SITE

CITY OF SAN JOSE, CALIFORNIA
DEPARTMENT OF NEIGHBORHOOD SERVICES
OFFICE OF THERAPEUTIC SERVICES
1530 BLOSSOM HILL RD., SAN JOSE CA 95118-3302
(408) 267-0200 (VOICE) (408) 723-2754 (TDD) (408) 267-2834 (FAX#)

September 29, 1993

Ann Oliver
2216 Deodara Drive
Los Altos, California 94024

Dear Ann,

This letter is to give you permission to conduct a study with Parkinson's Exercise program participants who have given prior consent. This research study entitled "Knowledge of Parkinson's Disease: A study of Older Adults in Santa Clara County" will be the only research project. In addition, Merry Lee Hooks, OTR, who is the program instructor, will also need to give you verbal agreement to pursue this study.

Once you receive permission from the University to conduct this research, an additional Memorandum of Agreement will need to be completed.

Sincerely,

Gary Okazaki, MPH, CTRS
Therapeutic Supervisor - Outreach Section

GO/go

cc: Merry Lee Hooks
Herm Shaver

APPENDIX E

INFORMED CONSENT FOR SUBJECTS

SJSU SAN JOSE STATE UNIVERSITY

A campus of The California State University

School of Applied Arts and Sciences • Gerontology Education & Training Center
One Washington Square • San Jose, California 95192-0140 • 408/924-3290

Agreement to Participate in Research

Responsible Investigator: Ann P. Oliver

Title of Protocol: OLDER ADULTS' KNOWLEDGE OF PARKINSON'S DISEASE

Location: _____

1. I have been asked to participate in a research study investigating older adults' knowledge of Parkinson's disease.

2. I will be asked to complete a questionnaire and a quiz at above location.

3. I understand that any risk to myself will be minimal.

4. I understand that from participation in the study I will gain information about Parkinson's disease.

5. The results of this study may be published, but no information that could identify me will be included.

6. I understand that there will be no compensation for participation in this study.

7. Any questions about the research may be addressed to the investigator, Ann Oliver, at (415) 968-0379.
Any complaints about the research may be presented to Debra David, Ph.D, Gerontology Department Chair, at (408) 924-2972.
Questions or complaints about the research, my rights, or research-related injury may be presented to Serena Stanford, Ph.D., Associate Vice President of Graduate Studies and Research, at (408) 924-2480.

8. No service of any kind, to which I am otherwise entitled, will be lost or jeopardized if I choose to "not participate" in the study.

9. My consent is given voluntarily. I may refuse to participate in the study or in any part of the study. If I decide to participate in the study, I am free to withdraw at any time without prejudice to my relations with San Jose State University or any other participating institutions.

10. I have received a signed and dated copy of this consent form.

- **The signature of a subject on this document indicates agreement to participate in the study.**

- **The signature of a researcher on this document indicates agreement to include the above named subject in the research and attestation that the subject has been fully informed of his or her rights.**

Subject's Signature	Date
Investigator's Signature	Date